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SPIRITUALITY IN PALLIATIVE CARE: OPPORTUNITY OR BURDEN?

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SPIRITUALITY IN PALLIATIVE CARE: OPPORTUNITY OR BURDEN?

Abstract

The article questions an assumption in palliative care literature, namely that all patients have a spiritual dimension and that all staff can offer spiritual care. The article identifies spirituality as a particular kind of discourse. In late-modern Anglophone societies, this discourse arises from the experience of a particular generation and a particular segment of the population, namely those moving beyond formal religion; this segment is probably better represented among caring professionals than among dying patients. A four-fold typology of patients' approaches to religion/spirituality is developed, indicating the potential of differentiating between actual patients, rather than presuming a universal 'search for meaning'. This alternative approach may enhance opportunities for team-working and reduce the likelihood of any one member of staff feeling spiritual care to be an unwelcome burden.

Keywords:

spirituality, religion, palliative care, nursing,

SPIRITUALITY IN PALLIATIVE CARE: OPPORTUNITY OR BURDEN? *

Introduction

Palliative care is formally committed to holistic - that is, physical, social, psychological, spiritual - care of the dying person and their family. This article asks to what extent spiritual care can be an integral part of palliative care, and questions some claims made in the literature.

In healthcare and nursing textbooks ^{1 2 3 4} and in numerous multi-professional workshops in the UK and USA, though not routinely in nursing practice, spirituality is presented as the human search for meaning. This view states: 1) though not all patients are religious, all are spiritual in the sense that they have existential concerns about the meaning of their life; 2) because everyone has spiritual concerns which need not be religious, any member of the palliative care team (whatever his or her own religion or lack of it) can provide spiritual care. Spiritual care is thus difficult to differentiate from socio-psychological-emotional care, though - as Kellehear has observed ⁵ - a number of its proponents are zealous in differentiating it from religious care. This separation of spiritual care from religion is more often articulated by nurse authors than by chaplain authors, and more often in Britain than in less secular countries.

If all patients have spiritual needs, if the palliative care unit is committed to holistic care, and if all members of the multi-disciplinary team can deliver this kind of spiritual care, logic then requires that they ought to deliver it. As an advert for a spiritual care workshop at St Christopher's in 1999 announces: 'This workshop assumes that all health professionals working in palliative care share responsibility for the spiritual needs of patients and families. The day...takes a broad view of spirituality.' A similar message comes from other workshops on spiritual care. Babler's survey of U.S. hospice nurses, social workers and spiritual care providers (which as a replacement term for 'chaplain' reveals a distancing from institutional religion) made the unsurprising finding that spiritual care providers provided more spiritual care than did nurses and social workers. ⁶ Babler concluded from this that nurses and social workers need more training in this area. This conclusion is surprising - a survey that found that chaplains or social workers provided less nursing care than nurses would never be taken to imply that social workers or chaplains need more nursing training. The publication of this article in a leading American hospice journal indicates how it is taken for granted that all hospice staff ought to be providing spiritual care for all their patients, despite practice being otherwise.

In this extension from 'can' to 'ought', spiritual care becomes not just an opportunity for palliative care nurses, but a responsibility. Sloan et al have questioned on ethical grounds the offering of religious care such as prayer,⁷ suggesting it might constitute an invasion of patients' privacy, though Small argues that contemporary spiritual care is less controlling than old style religion and may even be emancipatory. ⁸ This article, however, poses a different question: can all staff provide spiritual care to all patients who are searching for meaning? If the answer is in any way negative, this would have implications for practice. What appears an exciting new responsibility for the nursing and other professions may turn out to be an unwelcome burden. This article examines this question by examining the language, or discourse, of spirituality in the contemporary English speaking world. Whereas most publications on spiritual care in health have looked solely at health care, this article uses the comparative

method - examining discourses of spirituality in other contexts - to illuminate their use within health care.

The Anglophone context

The notion of spirituality as the search for meaning was introduced to palliative care through Cicely Saunders' ⁹ reading of Austrian psychiatrist Viktor Frankl, author of Man's Search for Meaning.¹⁰ Frankl himself termed this an existential, rather than a spiritual, search; it is primarily the English who have replaced the term 'existential' with 'spiritual'.

Saunders and Kastenbaum's global survey of hospice care ¹¹ unwittingly reveals this notion of spiritual care to be restricted largely to the English speaking world. Chapters from France, China and Hong Kong see spiritual care entirely in terms of care by religious professionals, while many other chapters fail to mention it at all. Markham concludes that 'the search for spirituality in health care is primarily an Anglo-American debate', and that the notions of spirituality dominant in this debate are very different from traditional spirituality in most world religions; for Markham, they resemble a secularised version of Christianity.¹² Bradshaw differentiates contemporary 'spirituality' from historic Christianity: 'Traditional, orthodox spirituality, the human being in relationship to God, has been replaced by a conception of spirituality as a personal and psychological search for meaning.'¹³

The English-speaking world is, historically and culturally, largely a Protestant Christian world. A recent study of hospital chaplaincy in London ¹⁴ found it was Protestant, not Catholic or other faith, chaplains who advocated nurse involvement in spiritual care. We have, therefore, a language of spirituality that is being promoted in the secular health care facilities of the English speaking part of the Protestant world. It is rarely found in Catholic, profoundly religious, or non-English speaking countries.

Organisations and individuals

Most authors proposing this personal and psychological view of spirituality in health care are nurses, writing in nursing journals and text books. Walter has argued that this view of spiritual care, if put into practice, would expand the role of nurses and meet specific organisational problems in secular and multi-faith hospitals. It promises, for example, to solve the tricky problem of how non-religious staff can provide spiritual care for non-religious patients. Similarly, staff of one religion can assist patients of another religion. 'The great advantage of this approach is that spiritual care can be provided regardless of the staff member's own faith or lack of it. It can be provided by anyone, for anyone.'¹⁵

Broadening the definition of spirituality beyond traditional religious concerns is not just a response to organisational needs within health care. Similar organisational needs exist within the British education system, which - unlike the American - is required to provide a spiritual dimension to education, even though most teachers and pupils do not adhere to any formal religion, and an increasing proportion of those that do are adherents of non-Christian religions. Similarly broad definitions of spirituality are emerging in educational literature in the UK. OFSTED, the British school inspection agency, defines spiritual development as relating

to that aspect of inner life through which pupils acquire insights into their personal existence which are of enduring worth. It is characterised by

reflection, the attribution of meaning to experience, valuing a non-material dimension to life, and intimations of an enduring reality. 'Spiritual' is not synonymous with religious, all areas of the curriculum may contribute to pupils' spiritual development.¹⁶

This definition supposes that all children - whether or not religious - develop spiritually, though it includes in this not only the search for meaning but also 'the non-material' and 'intimations of an enduring reality'.

A number of theologians and writers on religion are also broadening the definition. One feminist theologian writes:

Spirituality can be described as a process of transformation and growth, an organic and dynamic part of human development..... an exploration into what is involved in becoming human..... the way in which a person understands and lives with his or her historical context.¹⁷

In this definition, even sociology - which certainly provides a 'way in which a person can understand and live with his or her historical context' - would become part of spirituality. That this most historically secular of disciplines should qualify indicates how broad spirituality has become: the academy, personal development, and health care all become ways of developing personal spirituality. So we find that a broad discourse of spirituality arises not just in palliative care, not just in nursing, but in other contemporary arenas.

Who is promoting this broad discourse of spirituality, why, and why now? It represents a critique of scientific reductionism; in health care, discourses of spirituality bring back the human, the personal and the emotional into an arena otherwise dominated by medical and financial rationality.^{12 18} But discourses of spirituality represent a critique not only of rationalism, but also of religion. Clues may be found in the repeated distancing of 'spiritual' from 'religious' as found in the OFSTED definition and in numerous nursing and palliative care texts, and in the emphasis on personal development as opposed to organised religion. 'Spirituality' moves beyond science, and moves beyond institutional religion. This resonates with several features of many modern, and in particular Anglophone, societies:-

1) English speaking societies are particularly individualistic, for deep rooted but as yet not entirely understood historical reasons.¹⁹ Under recent conditions and prompted by Thatcherism and the collapse of both communist practice and socialist ideals, individualism has been gaining ground globally. The new spirituality is specific to the individual, an inner quality that may be furthered through one-to-one dialogue with a spiritual adviser, counsellor or health care worker, but can stifled by formal religious organisations, hierarchies and creeds.

2) Associated with individualism is a distrust of institutional authority. I will believe whatever seems right to me, not what the church or any other authority tells me. This 'authority of the self' typifies not only New Age and other new forms of spirituality,²⁰ but also many other arenas. The authority of the modern consumer takes over, in theory at least, from the authority of the expert;²¹ the globally growing charismatic movement privileges personal experience of the Holy Spirit over the authority of traditional Catholic or evangelical teaching;²² palliative care is driven, in principle at least, by the elicited wants of the patient rather than by doctor's orders.²³

3) One reason that institutional authority in religion has been undermined is that its ability to provide coherent and mutually consistent answers to the questions 'Where have we come from?', 'What happens after we die?' and 'What is the basis of morality?' has fragmented in the face of competing answers from science and social science.²⁴ These are, of course, precisely the questions addressed within both education and palliative care's discourse of spirituality. The answers can no longer be authoritatively provided by church dogma, but have to be personally engaged with. Provisional, situation-specific answers replace divine revelation, as Frankl himself noted. Further, the transformation of western society into a multi-faith society undermines the authority of any one religion - at least for many Christians and Hindus, less so for Muslims.²⁵

It is in these three contexts that institutional and dogmatic religious discourses are being challenged by a wider, yet more individual and personal, discourse of spirituality.²⁶

Spirituality and religion

More specifically, current discourses of spirituality have been generated by a particular segment of a particular generation. The Encyclopaedia of Religion and Society, defines spirituality as follows:²⁷

Frequently used, but ill-defined, term; most generally understood as a quality of an individual whose inner life is oriented toward God, the supernatural, or the sacred. Recalling William James' distinction between personal experience and inherited tradition, it is increasingly common to contrast 'spirituality' with 'religion'.

Spirituality is considered primary, more pure, more directly related to the soul in its relation to the divine, while religion is secondary, dogmatic and stifling, often distorted by oppressive socio-political and socio-economic forces..... American baby boomers frequently rejected organised 'religion' in favor of individual 'spirituality'. The return to or recovery of spirituality was central to the cultural ferment of the 1960s in America, and the term spirituality is therefore often modified by adjectives associated with some of the major cultural movements of the 1960s and post-1960s era, including New Age spirituality, postmodern spirituality, and most notably, feminist spirituality.

Spirituality is a term used by those contemporary Britons and Americans who are moving away from or beyond institutional Christianity, but who still have some sense of the numinous and (cf the OFSTED terminology) 'the non-material', who still have 'intimations of an enduring reality'. They wish to express this, while distancing themselves from the institutional church, its language or its personnel. Though some nursing and palliative care texts include in their definition of spirituality some reference to the supernatural or the sacred as part of the search for meaning,^{2 3} and some refer simply to the search for meaning,⁴ almost all share the feature highlighted by the encyclopaedia entry: the separation of the spiritual from the religious. They see religion as a codified, institutionalised and relatively narrow expression of spirituality.

Just as scholars can never agree on a definition of religion, so there is unlikely ever to be agreement on a definition of spirituality. But we may venture a socio-linguistic description. Spirituality is a discourse used at the present time in the English-speaking world by those who wish to move beyond, or distance themselves from, institutional religion. However vaguely the word 'spirituality' is

used, it *does* tell us for certain where those who use it have come from (institutional religion), and where they see themselves as going (somewhere else). A significant minority are articulate writers and communicators, and have considerable influence.

A particularly prominent language of contemporary spirituality is feminist spirituality. Many more women than men in Britain and North America have religious sensibilities,²⁸ and spirituality has now become a significant discourse for many devout women who dislike the domination of church leadership and theology by men.¹⁷ If religion has to do with the institutional, and therefore patriarchal, church, then it is spirituality that such women seek. Spirituality is largely, but not entirely, a female discourse, just as healing and caring are. Christianity, femaleness and the caring professions have been associated since at least the nineteenth century, so the discourse of spirituality - the discourse of devout women moving beyond the institutional church - is heard particularly strongly in the caring professions, and not least in health care.

Of course, not all nurses are, or were, religious (nor for that matter female). They, like schoolteachers from a non-religious background, have to be consciously taught both the newly approved meaning of the term 'spirituality', and that it is different from religion. This is precisely what workshops for nurses on spiritual care do. The successful workshop takes non-religious nurses who are troubled by, or indifferent to, the requirement for them to provide spiritual care, and persuades them that everyone has a spiritual search for meaning, that this is different from formal religion, and that nurses can play a significant role in providing spiritual care.^{1 4}

What about hospice and hospital chaplains? Though clearly religious, they too have by definition moved beyond the institutional church. In the UK, they are employed by a secular NHS. Though little research has been conducted into them,¹⁴ it seems that some choose chaplaincy precisely because it is removed from the organised church. The more conservative forms of religion, whether evangelical, charismatic or Catholic, are carried by congregations, so clergy removed from congregational pressures find themselves freer to explore ministry in personally and theologically adventurous ways.²⁹ Compared to congregational clergy, a disproportionate number of chaplains in health care are women, and it may be that a disproportionate number are also gay, both groups having been kept at arms length by most churches.

Prophetic vision or passing fad?

Whereas this article argues that the discourse of spirituality is generated by a particular historical generation and in particular institutional contexts, Edward Bailey places this on the grand stage of social evolution.³⁰ He proposes a development from the primitive religion of small scale societies, through the world religions developed by historical societies, to the diffuse spirituality of multi-cultural urban societies. He suggests this evolution is paralleled within the modern individual's life course,³¹ in which the child who has a sense of the sacred becomes the young adult who embraces a world religion, who in turn becomes the mature adult who develops a personal spirituality:

<u>Society</u>	<u>Life course</u>	<u>Religiosity</u>
small scale	child	the sacred
historical	adolescent/young adult	the holy (world religions)

urban

mature adult

spirituality

In Bailey's view, spirituality is the discourse of the future, and those who employ it are prophetic. There is some evidence for this in that talk of spirituality has developed in certain complex urban societies. But at the present time - contra Bailey - it tends to be young and middle aged adults, rather than the elderly, who speak of spirituality. We will have to wait and see whether Bailey is correct that spirituality is a discourse that will come to characterise complex urban societies, or whether it will prove to have been a short-lived discourse of a generation or two as it moved away from religion in a rapidly de-traditionalising late twentieth century.

What we do know is that a) it is a discourse used, indeed vigorously promoted, by many of those moving beyond or from religion, b) these people are not representative of the entire population, but c) are likely to constitute a disproportionate number of health care workers, especially nurses and chaplains.

Four types of discourse

In order to locate discourses of spirituality more precisely, we may compare them with two other discourses. One is the language of traditional religion, whether it be official religion or folk religion. A substantial proportion of the North American population sees religion and prayer as important in medicine, health and healing.⁸ Religiosity is particularly marked among the elderly who comprise a high proportion of hospital, and in particular palliative care, beds. To the extent that one belongs to a religious tradition, meaning is given or revealed by that tradition, rather than individually searched for. (Frankl himself argues that it is the loss of religion and of tradition that leaves many modern people with an existential vacuum which they must fill up with individually sought meanings.)

Another discourse is that of materialism, secularism or Humanism, the language of those who simply face life in its material/aesthetic aspects, but who believe that 'when you're dead, you're dead' and that there is no other realm beyond the material and the aesthetic, or if there is then there is no way of knowing it or talking about it.

Having identified these three discourses - spiritual, religious, and secular - we may break them down into two dimensions. One - particularly relevant to patients facing their own mortality - is whether they feel death to be the end or a beginning. Is physical life on this earth all there is, or is it an apprenticeship for an even more real life to come in heaven (or, as in many religions, for further incarnations on earth)? Or in the words of OFSTED, does the person have, 'intimations of an enduring reality'? This dimension, following Davie³², may be termed 'believing'. The other dimension, may be termed 'belonging', and it refers to whether belief is rooted in and/or expressed through the language and rituals of an institutionalised religious tradition or other belief system (such as Humanism). In England, with declining baptism and church attendance rates, many people believe in God and life after death without belonging to a church.³²

Combining these dimensions produces the 2 x 2 represented in Figure 1. (Fig 1 here.) This is not a typology of people, but of discourses. In the real world, an individual may use more than one discourse. 'Spirituality' is a discourse used predominantly by some in the bottom left-hand box and is a particular sub-set of believing without belonging. It is expressed by those who are moving beyond belonging (even if, in the case of chaplains, only in terms of employment), while

still believing. The typology recognises that some people are explicitly, others implicitly, secular; it does not impose the language of spirituality on everyone.

As with any sociological typology, the aim is not to stereotype people, but to provide a map of the terrain within which people think and act. Typologies highlight contradictions and conflict. Many British people move around between the two left-hand boxes. Having a terminal illness or bereavement, like other life-course crises,³¹ may move people around the terrain of faith, causing some to turn to, others away from, the institutional church. Bereaved churchgoers (top-left) may visit a spiritualist medium (bottom-left). Some may conclude that they do not believe in an afterlife after all; others³³ may come to embrace such a belief. Such movements may lead to considerable peace, or to a painful secondary loss as I find I am losing my faith as well as my life. Others just live with contradictions: one agnostic, on seeing a devoutly religious friend dead on her hospice bed, had a strong sense of her being at peace and with the God he did not believe in.

Implications

Are there policy implications of basing holistic palliative care on differentiating between demonstrably different kinds of believing/belonging, rather than on the presumption of a universal 'spirituality' in which each individual seeks their own meaning?

First, terminology. 'We all have spiritual needs even though we may not recognize them as such' is not an unusual statement from advocates of spirituality in health care.³⁴ I suggest, however, that the words 'spiritual' and 'spirituality' are probably best used only with reference to those patients who would themselves embrace them. There may well be an increasing number who do, but 'spiritual' remains a term that some traditionally religious and many irreligious patients do not employ. Sociologists are called to discover the meaning that people give to actions, and health care workers are called to sit and listen to their patients, so both should refrain from imposing terminology on patients that patients themselves do not use. We could see all the four boxes in Figure 1 as ways humans are given, or construct, meaning; but to see them all as spiritual, which most writing on spirituality in health care does, when only some of those in only one or at most two boxes use that terminology, is poor social science and poor pastoral care.

The second, related, implication concerns research into euthanasia. Cicely Saunders' identification of 'total pain' has proved of value in alerting health workers to pain's complex causes, but the concept of 'spiritual pain' as used by her and others³⁵ is much less precise. What palliative care workers call 'spiritual pain' is often more accurately labelled 'biographical pain',³⁶ namely the sense that my life has not added up in the way I would have wanted, and impending mortality means that this is now too late to change. High levels of biographical pain exist among old people in Britain,³⁶ much higher than in Canada,³⁷ this difference being as yet unexplained. If the debate on euthanasia is to be better informed, more research needs to be conducted into this. The claim that everyone can find meaning in life is a key part of the hospice movement's stance against euthanasia. It is an empirical claim, and one that needs empirical testing. Empirical research here as elsewhere needs to use clearly definable and operationalisable terms: biographical pain is one such, spiritual pain is not.

The third policy implication concerns who can help whom. Critics of a medical model of palliative and bereavement care have proposed a model in

which, rather than offering treatment, the carer accompanies³⁸ or companions the dying or bereaved person³⁹ or shares their journey.⁴⁰ Death and loss, like birth, are natural processes, and workers in these fields are therefore akin to midwives. The dying or bereaved person is making a highly personal pilgrimage, and the carer walks with them some of the way. This paper raises the question whether, or how far, each carer can walk with each patient? Can anyone who sits lightly to her own convictions and employs listening skills accompany anyone and everyone on their unique last journey or on their unique path of grief? Looked at in terms of a universal search for meaning in which each individual has to seek a unique path, one is tempted to answer yes, and this is the message given by most teachers of spiritual care for health care workers.

Looked at, however, in terms of the radical differences between those who believe in an afterlife and those who do not, and between those who subscribe to a formally recognised belief system and those who do not, one is tempted to answer no. One Christian hospice chaplain explained away a bereaved client's sensing the presence of her dead husband, seeing it as a functional but ultimately illusory hallucination. This reductive explanation is common in the psychiatric literature, but would be rejected by any self-respecting phenomenologist committed to taking the person's religious experience seriously in its own terms. This otherwise open-minded chaplain was unable to take this widow's experience in its own terms partly because of his belief, deep within the Protestant tradition, that communication with the dead is wrong and partly because of being influenced by secular psychiatry.

Or to take another example. A devout evangelical, while being given chemotherapy in a leading London cancer hospital, was also routinely offered a range of complementary therapies such as massage, reflexology, and counselling. She was disturbed by the offer of some of these therapies, which she saw as New Age and anti-Christian. It seems unlikely that all these therapists would have been able to enter her worldview and support her during her visits to the chemotherapy clinic; traditional prayer from another believing Christian would have been more appropriate.

We might therefore be well advised to drop the assumption that any health care professional can offer spiritual care to any patient, and to attend more carefully to the differences between and among patients and staff. It may be that many Hindus can only be accompanied by other Hindus. It may be that some Christian widows who sense the presence of their dead husbands can not be accompanied by those Christian clergy who cannot take this experience seriously; they may actually find a non-religious person a better companion. If this be so, then there will be no clear prescriptions for who can accompany whom. Though hard to operate outside well-funded hospices,⁴¹ this nevertheless fits two precepts of palliative care rather well: 1) every patient is different, 2) care must involve the whole team. It might also have implications for multi-cultural staffing. With careful attention being paid to each individual patient, and with knowledge of what each member of the team can and cannot offer, it may be possible to find someone who can accompany each patient at least a little of the way. But it need not be me. This should relieve each member of the team of the burden of feeling obliged to accompany each and every patient.

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Figure 1. Four types of discourse

**BELONG TO
A CHURCH
(or other formal
belief system)**

BELIEVE IN GOD / AFTERLIFE

	YES	NO
YES	<i>Formal religion</i> Christianity / Islam / Hinduism / Buddhism	<i>Explicit secularism</i> Humanism Atheism
NO	<i>Folk religion</i> (reunion in heaven, contact through mediums, etc) <i>Spirituality</i> (New Age, feminist, etc)	<i>Implicit secularism</i> 'When you're dead, you're dead'

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